AMENDED IN ASSEMBLY JUNE 24, 2008

AMENDED IN SENATE MAY 27, 2008

AMENDED IN SENATE APRIL 22, 2008

AMENDED IN SENATE MARCH 24, 2008

**SENATE BILL** 

No. 1364

## **Introduced by Senator Cedillo**

February 21, 2008

An act to add and repeal Part 2.5 (commencing with Section 104340) of Division 103 of the Health and Safety Code, relating to autism spectrum disorders.

## LEGISLATIVE COUNSEL'S DIGEST

SB 1364, as amended, Cedillo. Autism spectrum disorders: advisory council: centralized registry.

Existing law imposes various functions and duties on the State Department of Public Health with respect to the administration and oversight of various disease prevention and health promotion programs.

This bill would require the department, by January 1, 2010, to establish the Autism Spectrum Disorders Advisory Council composed of 18 members, with 6 4 members each to be appointed by the Senate Committee on Rules, 4 members to be appointed by the Speaker of the Assembly, and 10 members to be appointed by the Governor. This bill would require the council to provide recommendations to the department to enable it to deal more effectively with the public health crisis of autism spectrum disorders. The bill would provide that the council shall be convened only upon a determination by the Department of Finance that sufficient private donations have been collected and deposited into

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the Autism Spectrum Disorders Public Health Program Fund to fully support the activities of the council.

This bill would also require the department, to the extent that funds are deposited in the Autism Spectrum Disorders Public Health Program Fund for this purpose, in partnership with the council, the State Department of Developmental Services, the State Department of Education, and other appropriate state and local agencies, to establish a pilot project in 3 or more consenting counties that will provide a voluntary centralized registry of individuals with autism spectrum disorders.

This bill would require the department, on or before June 1, 2012, to submit a report to the Governor and the Legislature with recommendations from the council.

This bill would establish the Autism Spectrum Disorders Public Health Program Fund in the State Treasury, would require the department to deposit any moneys available for purposes of the bill into the fund, and would permit the department to use moneys in the fund, upon appropriation by the Legislature, to implement the bill. The bill would provide that the council shall be convened and the registry implemented upon a determination by the Department of Finance that sufficient private donations have been collected and deposited into the fund for these purposes, as prescribed.

This bill would make its provisions inoperative on July 1, 2012, and repeal them on January 1, 2013.

Vote: majority. Appropriation: no. Fiscal committee: yes. State-mandated local program: no.

*The people of the State of California do enact as follows:* 

- SECTION 1. The Legislature finds and declares all of the following:
- 3 (a) Autism spectrum disorders are now the fastest growing 4 serious developmental disabilities in California and affect one in 5 every 150 children and one in 94 boys.
  - (b) Most school districts in California have seen a doubling of students with autism spectrum disorders in the past four years alone. The number of Californians with autism spectrum disorders
- 9 who are served by the State Department of Developmental Services
- 10 now exceeds 35,000, which is a number that has more than tripled
- since 1998 and has increased more than twelvefold since 1987.

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(c) Many Californians are not adequately informed about autism spectrum disorders and the value and importance of early identification, assessment, and treatment of these disorders.

- (d) Individuals with autism spectrum disorders and their families in underserved populations face tremendous and overwhelming challenges in accessing and navigating the complex programs and services for these disorders.
- (e) Programs and services that serve individuals with autism spectrum disorders typically lack appropriate data management and information sharing systems, which has precluded California from accessing federal funding and resources.
- (f) Autism spectrum disorders are a public health crisis, and yet the state lacks a comprehensive public health initiative and infrastructure.
- (g) The State Department of Public Health has been established to improve access to health care services, and this department currently has an impressive record of autism study and research within its Environmental Health Investigations Branch.
- SEC. 2. Part 2.5 (commencing with Section 104340) is added to Division 103 of the Health and Safety Code, to read:

## PART 2.5. AUTISM SPECTRUM DISORDERS

104340. As used in this part, the following terms shall have the following meanings:

- (a) "Council" means the Autism Spectrum Disorders Advisory Council.
- (b) "Department" means the State Department of Public Health. 104340.5. (a) The department shall establish the Autism Spectrum Disorders Advisory Council by January 1, 2010.
- (b) The council shall consist of 18 members, six four members appointed by the Senate Committee on Rules, six four members appointed by the Speaker of the Assembly, and six ten members appointed by the Governor.
- (c) The council shall reflect the diverse and multicultural population of California and shall include at least one representative from each of the following:
- (1) Individuals with autism spectrum disorders or their family members.

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(2) Individuals with experience and expertise in the field of biomedical research related to autism spectrum disorders.

- (3) Individuals with experience and expertise in the area of public health issues related to autism spectrum disorders.
- (4) Individuals with experience and expertise in the area of autism spectrum disorder issues related to underserved communities.
- (5) Individuals with experience in the area of community outreach, education, or public relations related to autism spectrum disorders.
- (6) Individuals with experience and expertise in services and programs provided by regional centers or the State Department of Developmental Services.
- (7) Individuals with experience and expertise in programs and services for autism spectrum disorders through special education.
- (8) Individuals with experience and expertise in programs and services provided to adults with autism spectrum disorders.
- (9) Individuals with experience and expertise in programs and services related to autism spectrum disorder medical treatments and interventions.
- (10) The council shall be chaired by the State Public Health Officer or his or her designee.
- (d) The council shall be convened pursuant to this part only upon a determination by the Department of Finance that sufficient private donations have been collected and deposited into the Autism Spectrum Disorders Public Health Program Fund to fully support the activities of the council.
- 104341. The council shall provide input and make recommendations to the department that will enable the department to deal more effectively with the public health crisis of autism spectrum disorders. These recommendations may include, but are not limited to, the following issues:
- (a) Strategies to enhance public awareness of the signs and manifestations of autism spectrum disorders.
- (b) Strategies to enhance public awareness of the importance of early screening, diagnosis, assessment, intervention, and treatment of autism spectrum disorders.
- (c) Strategies to enhance partnerships between public and private entities and to mobilize all available resources to address the public health crisis of autism spectrum disorders.

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(d) Strategies to improve access to, and navigation of, programs and systems that provide services to individuals with autism spectrum disorders and their families.

- (e) Strategies that will improve and provide needed services to underserved communities.
- (f) Strategies that will provide improved coordination and integration of programs and services for *persons with* autism spectrum disorders at the state, regional, county, and community levels.
- (g) Strategies that provide recommendations and input on existing programs at the department that are potentially related to autism spectrum disorders, including, but not limited to, the California Environmental Contaminant Biomonitoring Program provided for pursuant to Chapter 8 (commencing with Section 15480) of Part 5, and other programs administered by the Environmental Health Investigations Branch.
- 104342. (a) The department, in partnership with the council, the State Department of Developmental Services, the State Department of Education, and other appropriate state and local agencies shall establish a pilot project in three or more consenting counties that will provide a voluntary centralized registry of individuals with autism spectrum disorders.
- (b) A registry created pursuant to subdivision (a) shall ensure the confidentiality of all participants and comply with all existing federal and state confidentiality laws and regulations.
- (c) The goals and objectives of the pilot project shall include, but not be limited to, demonstrating the value of a centralized registry with regard to the following:
- (1) Planning, administering, and delivering programs and services related to autism spectrum disorders.
- (2) Future public health services related to autism spectrum disorders.
  - (3) Future research related to autism spectrum disorders.
- (d) This section shall be implemented only to the extent that funds are deposited in the Autism Spectrum Disorders Public Health Program Fund for this purpose.
- 37 104343. The department shall submit a report to the Governor 38 and the Legislature on or before June 1, 2012, that includes all of 39 the following:

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(a) Recommendations and strategies that were provided by the council to the department.

- (b) Findings and recommendations about implementing a voluntary centralized registry for individuals with autism spectrum disorders.
- (c) Findings and recommendations about the future of the council.

104344. The department and the council may partner with existing public and private programs and initiatives to share information, avoid duplication, and build upon the work and recommendations of reports and published models regarding autism spectrum disorders.

104345. (a) The Autism Spectrum Disorders Public Health Program Fund is hereby created in the State Treasury. The department shall deposit into the fund any federal or state funds or private donations that are available for purposes of this part. Notwithstanding Section 16305.7 of the Government Code, any interest or dividends from money in the fund shall accrue to the fund. Moneys in the fund may be used by the department, upon appropriation by the Legislature, to implement this part.

(b) The council shall be convened and the registry implemented upon a determination by the Department of Finance that sufficient private donations have been collected and deposited into the Autism Spectrum Disorders Public Health Program Fund for these purposes. In the event that sufficient funds are not available to fund both the council and registry, the funds that are available shall first be used to convene the council and then, upon receipt of sufficient funds, the implementation of the registry.

104346. This part shall become inoperative on July 1, 2012, and, as of January 1, 2013, is repealed, unless a later enacted statute, that becomes operative on or before January 1, 2013, deletes or extends the dates on which it becomes inoperative and is repealed.